

Family Resource Guide



Welcome!

Being the parent, family member or caregiver of a person with an intellectual or developmental disability can be a completely unexpected experience. You have to find your way around programs, medical specialties, education programs, forms, websites and acronyms – it can be overwhelming. We hope this handbook makes the process a little easier.

At the Tennessee Department of Intellectual and Developmental Disabilities (DIDD), we want to work with family members and caregivers of people with intellectual disabilities. This guide will help you understand what services are available and how to go about receiving them. While this guide mainly focuses on services provided by DIDD, there is some additional information included that may be helpful as well. We've also included a few tips from other families about how to make the system work for you.

We hope this guide will help you navigate the system. For over 50 years, we have been making sure that Tennessee residents with intellectual and developmental disabilities receive quality services and supports. We look forward to working with you to continue that tradition.

What is DIDD and what does DIDD do?

The Department of Intellectual and Developmental Disabilities (DIDD) is a state government agency that has the responsibility to provide quality health and supportive services Tennessee residents with intellectual and developmental disabilities. To do that, we want to create opportunities for the people we support to control their lives as much as possible in the least restrictive environment. We also know it is important to partner with the people we support and their families in planning, developing and monitoring services and the way we provide them.

Our vision is to support all Tennesseans with intellectual and developmental disabilities to live fulfilling and rewarding lives.

Our mission is to become the nation's most person-centered and cost effective state support system for people with intellectual and developmental disabilities.

What is an intellectual disability?

A person with an intellectual disability has substantial limitations in functioning as shown by:

- ✓ An overall Intelligence Quotient (IQ) score of seventy (70) or below; and
- ✓ Below average adaptive skills such as:
 - Communication
 - Self care
 - Social skills
 - Community use
 - Self direction
 - Health and safety

Parent Tips!

- *Learn about your family member's disability and what it may mean for his or her development, skills and lifestyle.*
- *Learn your rights and your family member's rights regarding service eligibility, confidentiality and access; informed consent and decision-making; grievances and appeals; and policies/standards for providing services.*

To qualify for services through DIDD, onset of an intellectual disability must have occurred prior to age eighteen (18).

I'm seeking services. Where do I start?

If your family member has an intellectual disability and he/she or you want him/her to be placed on the DIDD waiver waiting list, your family member needs to have the following:

- ✓ Documentation of their disability and that disability being diagnosed before age 18. Acceptable forms of documentation include a special education "form" from their school that specifically states your family member has an intellectual disability; or a letter from your family member's physician.
- ✓ Proof he/she lives in Tennessee.
- ✓ Eligibility for Medicaid.
- ✓ A need for the same level of care a person would need if they were living in an institutional facility, known as an intermediate care facility for individuals with intellectual disabilities (ICF/IID).
- ✓ The ability to get services and supports that will keep him/her safe in the community.

The first step in getting on the DIDD waiver waiting list or to applying for services through DIDD is to contact the DIDD Regional Office in the area where your family member lives.

East Tennessee Regional Office (Knoxville)
[P] 888.531.9876 (toll free)

Middle Tennessee Regional Office (Nashville)
[P] 800.654.4839 (toll free) or 615.231.5382

West Tennessee Regional Office (Arlington)
[P] 866-372-5709 (toll free)

After contacting the Regional Office, an intake process will start. If your family member is added to the DIDD waiver waiting list, a Case Manager will be assigned and a home visit will be scheduled.

Parent Tips!

One of the most important things is to keep good records and documentation.

Because you are your family member's best advocate, collect information, stay involved, and participate.

Involve your family member in choosing services when appropriate and respect his/her point of view.

Ask professionals and agencies to provide written responses to your questions and requests.

During this process, DIDD will collect information about your family member and inform you of DIDD programs. DIDD refers to individuals we serve as a person supported. Once the intake assessment is complete, an intake specialist in the Regional Office reviews the assessment and evaluates the person's overall need for services.

What are waivers?

TennCare is the name of the Tennessee Medicaid Agency. It is also the name of the state's Medicaid Program for medical and behavioral care services. TennCare provides health care coverage for more than one million Tennessee citizens.

Medicaid programs are funded by the state and federal government, and they offer primary care and specialty health care. Medicaid provides waivers, which allow persons with intellectual disabilities to remain in the family home, live independently, or live in a community home instead of receiving those services in an institutional setting. This is known as a Home and Community Based Services (HCBS) waiver program. In Tennessee, these waivers are one way for people with intellectual disabilities to receive long term services and supports.

Currently, there are three HCBS waiver programs for persons with intellectual disabilities in Tennessee:

- Statewide Waiver
- Arlington Waiver (closed to new enrollment)
- Self-Determination Waiver

What kind of services are available through the waiver?

Once recommended to begin the waiver enrollment process, your Case Manager will help determine which waiver is right for you and for what services your family member qualifies. Your Case Manager will also help develop the initial plan of care and help develop a support plan specific to your family member's needs.

There are a wide variety of services available, depending on need, qualifications, and availability. These services include:

- ✓ **Adult Dental Services** – Services include fillings, root canals, extractions, dentures, and other dental treatments. Does not include preventative care.
- ✓ **Behavior Services** – Assessment and treatment of behavior that presents a health or safety risk to the person supported or others and/or behavior that significantly interferes with home or community activities.
- ✓ **Case Management** – Services to assist the person supported in obtaining and coordinating both paid services and natural supports for community integration.
- ✓ **Day Services** – Services and supports that teach and improve skills that support semi-independent living.
- ✓ **Environmental Accessibility Modifications** – Interior or exterior physical modifications to the home that are required for health, welfare and safety or help to function with greater independence.
- ✓ **Nursing Services** – Skilled nursing services provided directly to the person supported that are based on a physician's orders.
- ✓ **Nutrition Services** – Services provided by a licensed dietician or nutritionist to assess nutritional needs and provide counseling and education for food purchase, preparation, and assistance in eating.
- ✓ **Occupational Therapy** – Services to help improve or maintain the ability to perform activities of daily living.
- ✓ **Orientation and Mobility Training** – Services to assist a severely visually impaired person move independently and safely at home and in the community.
- ✓ **Personal Assistance** – Assistance with activities of daily living like bathing, dressing, and household chores.
- ✓ **Personal Emergency Response System** – An electronic device used in the home of the person supported to secure help in an emergency.
- ✓ **Physical Therapy** – Services to help increase ability to move around in different settings.
- ✓ **Residential Services** – Services vary depending on the capacity of the person supported. Typically a 24/7 service where the person resides in a home of their own, outside of their family's home.
- ✓ **Respite Services** – Services for when caregivers are not able to provide care for a short period of time.

- ✓ **Specialized Medical Equipment & Supplies and Assistive Technology** – Assistive devices, adaptive aids, controls or appliances that help with daily living. **Speech, Language, and Hearing Services** – Services range from providing effective communication methods to helping someone swallow safely.
- ✓ **Supported Employment** – Services to help the person supported work at a job in the community.

What is available for family members & caregivers?

In 1992, at the urging of disability advocates and families, the Tennessee legislature established the **Family Support Program**. The program is funded by state dollars and designed to assist people with severe and/or developmental disabilities and their families to remain together in their homes and communities. Family Support is not a substitute for more comprehensive services provided under other programs, including the Medicaid HCBS waiver, TennCare, Medicare, or private insurance.

The primary purpose of the program is to support:

- ✓ Families who have school-aged or younger children with severe disabilities
- ✓ Adults with severe disabilities who choose to live with their families
- ✓ Adults with severe disabilities not supported by other programs funded by state or federal funds

Helpful Tip!

The average amount is about \$1300 a year per person. Funding for Family Support is limited and not every family that qualifies receives funding.

Services can include, but are not limited to: respite care, day care services, home modifications, equipment, supplies, personal assistance, transportation, homemaker services, health-related needs, nursing and counseling.

Services are flexible and responsive to persons supported and their needs. An essential element of the Family Support Program is family involvement. Local and District Councils have been established and meet on a regular basis to oversee and provide advice on the distribution of local services.

For more information on the Family Support Program, call your regional office or visit www.tn.gov/didd/family_support:

- West Tennessee – [P] 901.745.7348
- Middle Tennessee – [P] 615.231.5470
- East Tennessee – [P] 865.594.9288
- Statewide – [P] 615.532.6552

Are there any services for people on the waiting list?

You are encouraged to contact the DIDD Case Manager when information or assistance is needed. A person's situation can change while they are waiting for services. When changes happen, it may mean that a person meets the criteria for a different category of need.

There are several programs in Tennessee that are just for **children**. Eligibility for these services are based on several factors including age, disability or diagnosis, family income, where the child/family lives, and availability in the program. Some of the programs that serve children with intellectual and developmental disabilities in Tennessee are:

Tennessee Early Intervention System (TEIS) – This agency, which is operated by the Tennessee Department of Education, provides the free service of offering information, referral and support for children birth through age two.

<http://www.tn.gov/education/teis/> ☎ 800-852-7157

Early and Periodic Screening, Diagnostic and Treatment (EPSDT) – This is Medicaid's child health program for children under age 21 that focuses on prevention and screening to detect health problems before they become more complex.

TennCare operates this program through TeNNderCARE.

<http://www.tn.gov/tenncare/tenndercare/special.shtml>

☎ 800-342-3145

Parent Tips!

- *Keep copies of information you gather or provide. Keep records of contacts with professionals and agencies, including date and type of contact; the person's name, title, agency and phone number(s); and a summary of important things discussed.*
- *If a professional uses words or phrases you don't understand, ask for an explanation in simple terms.*

Adults with intellectual and developmental disabilities may have need for some other supportive services as well. These are some of the services and programs that are often used by families we serve:

Tennessee Department of Human Services (DHS) – This department provides eligible low-income individuals and families with services such as safety net emergency services, job development, adult education, and self-sufficiency programs.

<http://www.tn.gov/humanserv/>

☎ 615-313-4700

Tennessee Housing Development Agency (THDA) –

This agency promotes safe and affordable housing for people who need help by offering programs for home ownership and rental assistance.

<http://www.thda.org/>

☎ 800-228-THDA (8432)

Legal Aid Services of Tennessee – Legal Aid provides low-income Tennessee residents with legal assistance and advocacy in areas such as housing, health care, social security and family law.

<http://www.tals.org/directory> (This site connects you to Legal Aid offices in your area.)

Your Case Manager can provide additional information about community resources that may be available to meet some needs while you are waiting for DIDD services.

Other Helpful Links!

Children's Special Services:

<http://health.tn.gov/MCH/CSS.shtml>

Disability Law and Advocacy Center:

<http://www.dlactn.org/>

Hearing Bridges:

www.hearingbridges.org

kidcentral tn:

<http://kidcentraltn.com/>

Tennessee Council on Developmental Disabilities:

<http://www.tn.gov/cdd/>

Tennessee Disability Coalition:

<http://www.tndisability.org/>

Tennessee Rehabilitation Center:

www.tn.gov/humanserv/rehab/trc.html

Tennessee School for the Blind:

www.tnschoolfortheblind.org

Tennessee School for the Deaf:

<http://tsdeaf.org>

Tennessee Voices for Children:

www.tnvoices.org

The Arc of Tennessee:

www.thearctn.org

West TN School for the Deaf:

www.wtsd.tn.org

Tennessee Disability Pathfinder

The Tennessee Council on Developmental Disabilities and the Vanderbilt Kennedy University Center for Excellence in Developmental Disabilities have established a joint project called Tennessee Disability Pathfinder. Tennessee Disability Pathfinder is a free, statewide information and referral service to help individuals with disabilities, service providers, and family members find disability-related services needed in their community. Assistance is available in all languages for individuals of all ages and all types of disabilities.

Website: www.familypathfinder.org [P] 800.640.4636

Email: tnpathfinder@vanderbilt.edu

Resources in English: www.familypathfinder.org

Resources in Spanish: www.caminoseguro.org

Cecilia Melo-Romie, DIDD Liaison for Individuals with Limited English Proficiency
[P] 615.875.9850 Email: cecilia.melo-romie@vanderbilt.edu

Service categories include and are not limited to the following:

Advocacy <ul style="list-style-type: none">• ADA Information and Assistance Arts & Recreation <ul style="list-style-type: none">• Arts & Music Programs• Camps and/or Summer Programs Education <ul style="list-style-type: none">• Developmental/Educational/Psychological Testing• Early Intervention Program for Young Children Employment Services <ul style="list-style-type: none">• Adult Day Services• Employment Resources	Health Information <ul style="list-style-type: none">• Dental Care Services• Durable Medical Equipment• Health Care Services• Health Insurance Information Housing Resources <ul style="list-style-type: none">• Emergency Shelters• Home Rehabilitation/Repair Service• Housing Information Immigrant and Refugee Resources <ul style="list-style-type: none">• Immigrant and Refugee Services Information Services <ul style="list-style-type: none">• Bilingual and/or Multilingual Staff Mental Health Resources <ul style="list-style-type: none">• Behavioral Services• Dual Diagnosis	State Agencies <ul style="list-style-type: none">• State Government Agencies• Statewide Organizations Support for Families <ul style="list-style-type: none">• Child Care Programs• Conservatorship and/or Special Trust• Family Support Program Provider• Financial Assistance• In-Home Assistance Programs Technology, Equipment, Aids <ul style="list-style-type: none">• Animal Aides• Assistive Technology Equipment• Emergency Alert Devices
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1 have questions. Who can help me?

In addition to the resources we have included in this document, you are always welcome to contact one of the DIDD Regional Offices with any questions you may have.

East

Langley Building
520 West Summit Hill Drive, Suite 201
Knoxville, TN 37902
[P] 865.588.0508

Middle

275 Stewarts Ferry Pike
Nashville, TN 37214
[P] 615.231.5047

West

PO Box 949
11437 Milton Wilson Road
Arlington, TN 38002
[P] 901.745.7200 or
800.308.2586 (toll free)

The Developmental Disabilities Health Care E-Toolkit

- The E-Toolkit was developed by the [Vanderbilt Kennedy Center for Research on Human Development](#), the [University of Tennessee Boling Center for Developmental Disabilities](#) and the [Tennessee Department of Intellectual and Developmental Disabilities](#).

- The E-Toolkit has great information about the health care needs people with disabilities.

- Make sure you tell your primary health care provider about the E-Toolkit.

<http://vkc.mc.vanderbilt.edu/etoolkit/>